CHALLENGES FACED BY PARENTS IN REHABILITATING CHILDREN WITH CEREBRAL PALSY: THE CASE OF NDOLA URBAN

BY

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DEPARTMENT OF GENDER STUDIES

JUNE 2006
DECLARATION

I, Christine C. Shimulopwe - Chikolwa, declare that this dissertation represents my own work. It has not previously been submitted for a degree at this or any other University and does not incorporate any published work from another dissertation.

Signature

Date 05/06/06
The University of Zambia approves this dissertation of Christine C. Shimulopwe Chikolwa as fulfilling part of the requirements for the award of the degree of Master of Arts in Gender Studies.
ABSTRACT

This study examined challenges of rehabilitation faced by parents of children with cerebral palsy in Ndola urban, Zambia. Cerebral palsy is an injury to the developing brain. This injury often happens before, during birth or in the first five years of life (Kapulisa, 1990). Usually individuals with cerebral palsy experience difficulties in producing movement, preventing movement or controlling movement. Experiences of both female and male parents in socially rehabilitating their disabled children were explored and compared. Social rehabilitation referred to characteristics of parents, such as age, sex, level of education and gender roles performed. Comparisons were made of the economic activity parents engaged in and how it related to social rehabilitation. The study further investigated actions taken by parents regarding social rehabilitation of their children.

Data was collected from a total number of 33 parents, female and male parents. All parents in the sample had children with cerebral palsy. Both the qualitative and quantitative methods were employed. Semi-structured questionnaires as well as the observation methods were used.

Results from frequencies of observed and computed data revealed that both female and male parents experience challenges of rehabilitation. The results further indicated that there were significant differences between female and male parents’ challenges of rehabilitation. Females exhibit more challenges in the areas of requiring help in childcare, cooking, cleaning the house, attending to other children, and performing other tasks, which are mostly house chores. Moreover, female parents also show more optimism and expect their children to achieve higher goals in life, such as becoming a doctor, nurse, teacher, or working as clergyperson. Male parents on the other hand expect their children to get ‘cured’ and to achieve ‘lower’ goals. However, both female and male parents indicated that they were involved in socially rehabilitating their children. Interestingly, both female and male parents expressed that they were not influenced by the gender of their children in deciding whether the child needed to be rehabilitated or not.
However, this study concludes that the gender of a parent influences rehabilitation of children with cerebral palsy. Challenges are greater for female parents than for male parents. Senior parents take on triple roles of being a mother, a wife and a worker. Nevertheless both parents take positive actions in searching for the 'cure' such as finding ways of making the child comfortable regarding their children's problems and social rehabilitation needs.

The dissertation is divided into five chapters. The first chapter comprises the introduction, theoretical framework, statement of the problem, objectives of the study, research questions, purpose of the study, significance of the study, and the structure of the study. Chapter Two gives a critical review of the literature while the methodology is discussed in Chapter Three. In the fourth chapter, results are presented. Chapter five gives the discussion whereas conclusion and recommendations are presented in Chapter six.
Dedicated to my husband Joseph M. Chikolwa and our children Kabwe, Chola and Chanda
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<th>Abbreviation</th>
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<tr>
<td>CBD</td>
<td>Central Business District</td>
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<tr>
<td>CBRC</td>
<td>Community Based Rehabilitation Centres</td>
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<td>CRPs</td>
<td>Community Rehabilitation Programmes</td>
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<td>GRZ</td>
<td>Government of the Republic of Zambia</td>
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<td>IDDP</td>
<td>International Decade for Disabled Persons (IDDP)</td>
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<td>ILO</td>
<td>International Labour Organization</td>
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<tr>
<td>INESOR</td>
<td>Institute of Economic and Social Research</td>
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<tr>
<td>KEPA</td>
<td>Zambia</td>
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<td>LCMS</td>
<td>Living Conditions Monitoring Survey</td>
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<td>MOLSS</td>
<td>Ministry of Labour and Social Securities</td>
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<td>NGOs</td>
<td>Non-Governmental Organizations</td>
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<td>SAP</td>
<td>Structural Adjustment Programme</td>
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<td>SPSS</td>
<td>Statistical Packages for Social Sciences</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>UNCPA</td>
<td>United Cerebral Palsy Association</td>
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<td>UNICEF</td>
<td>United Nations Children's Fund</td>
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<td>UTH</td>
<td>University Teaching Hospital</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<td>ZARD</td>
<td>Zambia Association for Research Development</td>
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<tr>
<td>ZAMISE</td>
<td>Zambia Institute of Special Education</td>
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<tr>
<td>ZCSO</td>
<td>Zambia Central Statistical Office</td>
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<tr>
<td>ZMOE</td>
<td>Zambia Ministry of Education</td>
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<td>ZNCRDC</td>
<td>Zambia National Campaign for Research Disabilities</td>
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OPERATIONAL DEFINITION OF TERMS

The terms used in this study are as follows:

Cerebral Palsy- injury to the immature brain.

Challenge- in the text is used interchangeably with ‘difficulty’ ‘problem’ ‘obstacle’ ‘hurdle’ ‘barrier’ or ‘burden’.

Children- In this study refers to individuals in the age group six months to 12 years.

Disability- restriction or limitation in ability to perform given tasks arising from an impairment or condition. Also refers to any inability to move, sit unsupported, feed oneself, etc. Unless otherwise stated.

Ex-Mental- someone who has been discharged from a mental or rehabilitational institution.

Family- a unit comprising mother, father, children and their relations. In this study includes both nuclear and extended family.

Gender- this focuses on the social construction of women’s and men’s roles and responsibilities. It can be defined as a psychological or cultural concept, which refers to one’s subjective feeling of femaleness or maleness.

Gender roles- functional responsibilities which maybe assigned by society and are influenced by cultural, political, religious or economic situation.

Impairment- used interchangeably with the word disabled when the words disabled/cerebral palsy are not used.
Parent- This refers to all individuals in the study who have children with cerebral palsy.

Poverty- a state of insufficient productive resources and income to ensure sustainable livelihood, access to and control over basic needs which include food, clothing, shelter and social services such as health, education, water and sanitation.

Rehabilitation- Rehabilitation tends to be explained from various perspectives. For instance, it is known to be relevant to the social, educational and vocational success of an individual. It is also an attempt to determine the disabled persons' present strengths and weaknesses and to point to the environmental gaps and failures that must be remedied if the disabled are to make more rapid progress and lead meaningful lives (Serpell, 1997). Consequently, rehabilitation improves the quality of life of the disabled as well as those surrounding them. Parents are therefore, encouraged to realise the contribution and benefits of intervention processes such as rehabilitation for their childrens' lives as well as for their own lives.

Sex- this refers to the biological make up of women and men

Sex role Stereotypes- rigidly held and over generalised beliefs that males and females by virtue of their sex pose distinct traits and characteristics.
Social Rehabilitation- refers to any social interventions employed to redress and improve the situation of parents in coping with the disabilities and challenges for their children such as homecare, school attendance and physiotherapy attendance.
CHAPTER ONE
INTRODUCTION

1.1 BACKGROUND

Internationally, there is growing concern and awareness of the situation of disabled persons and the challenges of social rehabilitation. For instance, the United Nations has described the lack of social rehabilitation services for the disabled as one of the major challenges facing parents and societies because it deprives disabled persons and their families from living meaningful lives, earning incomes, enjoying social services without discrimination and missing out on educational and employment opportunities (United Nations, 1998). This study investigated problems of social rehabilitation that parents with disabled children face in the copperbelt province of Zambia. In particular, the study focused on parents whose children have cerebral palsy in Ndola urban.

The study recognises that parents with disabled children experience many difficulties in raising and rehabilitating their children. However, the study concedes that these challenges should be viewed from varied perspectives to help parents identify factors that hinder them from engaging their children in rehabilitation. As a mother of a disabled child with cerebral palsy, the researcher's interest in the subject stemmed from the difficulties encountered in raising and socially rehabilitating a severely affected 10-year-old daughter with cerebral palsy in Ndola (the study site). This study sought to investigate socio-economic and environmental problems associated with social rehabilitation. In other words, how parents cope and what social rehabilitation
services are available to them, and if available, what benefits they derive from having social rehabilitation services.

The ultimate goal was to identify areas of social rehabilitation that parents find desirable in helping to find lasting solutions.

1.2 THEORETICAL BACKGROUND

1.2.1 Global perspective

International organisations such as the World Health Organisation (WHO) and the United Nations Children's Fund (UNICEF) have taken steps towards monitoring disability among children. An agreement on indicators for monitoring the health goals was reached during the World Summit for children. This was to monitor progress towards the goal of improving the protection of children in difficult circumstances, and consider recent rehabilitation service coverage (United Nations, 2002). Moreover, the United Nations reveals that there are over 500 million persons with disabilities worldwide or ten percent of the global population, and that approximately two thirds live in developing countries. If the impact of their families is taken into account, 50 per cent of the population is affected by disability (United Nations, 2000). Consequently, proportions of the disabled continue to increase with growth of the world population.

1.2.2 The American Picture

In America, the United Cerebral Palsy Association (UCPA) estimates that more than 500,000 Americans have cerebral palsy. It is pointed out that this is
despite advances in preventing and treating certain causes of cerebral palsy. The number of children and adults it affects has remained essentially unchanged or perhaps risen slightly over the past thirty years. Some of the major reasons advanced for the unchanging number of Cerebral Palsy children are due to improved intensive care, as more children are surviving who would have otherwise died. However, even with this picture in mind, it is observed that research is underway to improve care for these children. (Sheldon, 2003) http://www.un.org/esa/socdev/enable/monitor/ dme41.htm, 2002.

1.2.3 African View

In Tanzania, the state of the world’s children draws attention to the benefits of having ‘normal children’. Both the girl and boy children play an active role in aiding the economic survival of the family. Children become economically active as early as six years old: street vending, managing family shops, working at food stalls, carrying water for sale, gathering firewood, working on farms, grazing animals, selling vegetables, fishing or getting jobs as market porters (UNICEF, 2002). In addition to the above, UNICEF also reveals that children are involved in routine domestic chores such as washing, cooking, going to the market or shops and performing many other tasks. Parents with disabled or severely affected children do not enjoy such ‘benefits’ but lose them instead.
1.2.4 Incidence of Disability in Zambia

In Zambia, out of a total number of 256,690 disabled persons from a total de facto population of 9.3 million people recorded during the 2000 Census, the incidence of disability stands at 2.7 percent of the total disabled population compared to 0.1 percent in 1990 (CSO, 2002). This, however, does not mean that the proportion of the disabled to the total population increased significantly between the two intercensal periods. The increase in the percentage is attributed to the addition of three categories of disability in the 2000 Census of Population and Housing, thereby enabling greater capture of disabled persons. The three added categories were: partial visually impaired, hard of hearing and ex- mental, (which means someone who has been discharged from a mental or rehabilitational institution). These categories were not captured in the 1990 Census. The Copperbelt province, where Ndola is located, recorded a proportion of fifty-four point five percent (54.5%) of disabled persons. This depicts the highest province with disabled persons followed by Lusaka and Eastern provinces out of whole disabled population figure in Zambia (ZCSO, 2000).

1.2.5 History of Rehabilitation

In Africa rehabilitation started with the initiative of Mr Jairos Jiri in Zimbabwe, who established a school for the blind in 1912. However, in Zambia, rehabilitation for a long time was regarded as a responsibility of missionaries who took charge of rehabilitating disabled individuals. Some of such rehabilitation work included a school established in 1986 at St Mulumba in the Southern province of Zambia. This was an institutional rehabilitation centre.
This was because, at the time of independence, there was no public policy to educate disabled children. Primary schools that existed for the visually impaired were inadequate and were only run by missionaries (Tembo and Mutale, 1995).

In recent years, the emphasis has shifted from institutional educational rehabilitation to community-based rehabilitation. For example, in Ndola eleven (11) Community Based Rehabilitation Centres (CBRC) sponsored by the Catholic Diocese were established in 1992/3. The Catholic Church has continued establishing these centres in other communities. Some of which are Chipulukusu, Sinya, and Chifubu, to name but a few. Other educational/rehabilitation centres also exist such as the Ndola Central Hospital day care centre for rehabilitation of persons with disabilities, the Lions School for the visually impaired, the Holy family and the Italian school. Unfortunately, these schools cater for children or individuals with various disabilities other than Cerebral palsy. Furthermore, the units lack facilities for severely affected children such as those with profound conditions including those with cerebral palsy. This entails that parents of children with cerebral palsy are solely left with the responsibility of looking after their severely affected children in their homes (Times of Zambia: 13th December, 1998, Wolfendale 1996).

1.2.6 Types of Rehabilitation

There are various types of rehabilitation, ranging from educational, medical, social and vocational rehabilitation. The most common form of rehabilitation that is emphasised in Zambia is that of educational rehabilitation. For
instance, the Ministry of Education (MoE1996) upholds the principle that every individual has an equal right to educational opportunity. The MOE is therefore, working towards helping to cushion the ‘burden’ of parents in educating disabled children by trying to increase educational rehabilitation services for well over 250,000 children of primary school age with special educational needs arising from physical and mental causes. This is being done through establishing and integrating special educational units in mainstream public government schools.

In 1995, there were thirty-one (31) special education institutions with twenty-eight (28) at primary, one at secondary and two at tertiary levels. There were also eighty (80) Special Education Units in schools countrywide of which fifty one (51) were at primary and twenty nine (29) at secondary school level. However, although educational rehabilitation measures such as introducing the integrated special units in public (government) schools have been implemented in the past, government schools and physiotherapy programmes in hospitals, have not completely yielded positive results. These units have largely left out social rehabilitation services for severely disabled children (Times of Zambia: December, 1998).

Rather than providing services that directly focus on cushioning parents from effects of caring for severely disabled children, such as rehabilitation centres, special units in schools were introduced (GRZ 2000). A few years after introducing these special educational units, reports stated that due to non-

1.2.7 Cerebral Palsy Consequences

The physical problems presented by cerebral palsy are known as motor problems. These problems can be mild, moderate or severe. When the condition is very severe, the person is unable to move at all. Some children experience abnormal movement and posture, impaired sensation and developmental delay (Stanton, 1992). Generally, other impairments may also arise such as epilepsy or fitting, learning difficulties, speech defects or lack of speech, impaired vision, impaired hearing and poor health (Kapulisa, 1998). Therefore, most severely affected children with cerebral palsy cannot move, walk, talk, hear or even see.

1.3 THEORETICAL FRAMEWORK

There are various theories that have been advanced such as those given concerning gender roles performed by both female and male parents. Such theories are applied in explaining the roles that parents play and how these roles influence participation in social rehabilitation of disabled children. Therefore, the theoretical approaches discussed include the functional theory and the theory of cerebral palsy.

1.3.1 The Functional Theory

According to the functionalist viewpoint, in studying any given society, we should look at how its various ‘parts’ or institutions combine to give that
society continuity over time. This theory focuses on the division of labour between the sexes. One of its chief proponents, (Parsons 1999) states that women and men are different and for this reason play different roles that reflect in the division of labour. Parsons further points out that biological function such as child bearing determine the behaviour of women and these biological factors bind them. Men on the other hand, are freed from such functions and hence they engage in activities outside the home and as a result become inevitable breadwinners (Ibid 1999). In consideration of all these, Parsons argues that the division of labour between the sexes is natural and should be there. Parsons also observes that the divisions of labour bring about complementarities and interdependence, hence become functional. Therefore, based on the theory described above, gender roles played by parents of children with cerebral palsy in the present study were explored.

1.4 STATEMENT OF THE PROBLEM
In Zambia, efforts of rehabilitating children with cerebral palsy have failed to recognise the challenges that parents of such children face. Very little is known about the different roles that the female and male parents play in social rehabilitation. It is usually assumed that raising disabled children is more or less the same as raising children who are not disabled. Many also assume that both female and male parents take equal responsibility in rehabilitating disabled children. Moreover, there is a danger of equating educational or special schools to complete rehabilitation. Despite Ndola having a number of educational, medical and Community Rehabilitation Programmes (CRPs) for the disabled, these institutions are designed mainly for physically and other categories of mildly disabled individuals.
Moreover, there are no social rehabilitation services to cushion parents' challenges of rehabilitation where parents can go to in order to obtain or offer respite services. Notably, parents with severely affected children such as those with cerebral palsy struggle with social, economic and environmental hurdles that surround their lives. These parents are adversely disadvantaged and lack support services. With widespread gender biases against women, it may be assumed that female parents of disabled children take up some share of tasks and responsibilities as male parents in social rehabilitation. Above all, a number of studies such as Kasonde-Ngandu, 1986; Serpell, 1998 focused on children and not parents. Therefore, this study sought to identify and bring these differences to the fore.

1.5 PURPOSE

The purpose of this study was to investigate barriers of social rehabilitation for both female and male parents of children with disabilities. The study also shows the importance of parents in the everyday lives of the disabled children. Parents would further be helped to realise that they need to enhance social rehabilitation practice and act upon their challenges.

Other factors that the study explored were differences in parents' social rehabilitation, concerns and actions in Ndola urban. This information is vital in that support services for parents can be targeted at parents facing greater challenges. Moreover, this study looked at parents' responses to the problems of their disabled. By focusing on steps that parents take in seeking solutions to solving these problems, the purpose was to help both female and male
parents participate in social interventions for their children. Consequently, the study was therefore guided by the objectives stated below.

1.6 OBJECTIVES OF THE STUDY

The objectives of the study were to:

1. Determine background characteristics of parents with children who have cerebral palsy.

2. Determine background characteristics of children with cerebral palsy.

3. Establish challenges of rehabilitation faced by both female and male parents of children with cerebral palsy.

4. Assess whether or not there is gender bias in rehabilitation of children with Cerebral Palsy.

5. Establish actions taken by parents in responding to the social rehabilitation needs of their children.

6. Determine the gender roles performed by both female and male parents regarding social rehabilitation.

7. Make recommendations to programme managers and policy makers regarding improvements of social rehabilitation.

1.7 RESEARCH QUESTIONS

The study attempted to answer the following research questions:

1. What are the background characteristics of parents of children with cerebral palsy?

2. What are the background characteristics of children with cerebral palsy?
3. Are there differences in challenges faced by both female and male parents of children with cerebral palsy and are they significant and systematic between female and male parents?

4. Is there any gender bias in social rehabilitation of children with cerebral palsy?

5. Do gender roles performed by parents have an influence on the social rehabilitation of their children?

6. How do parents respond to the social rehabilitation needs of their children?

7. What information can benefit programme managers and policy makers on social rehabilitation?

1.8 SIGNIFICANCE OF THE STUDY

Social rehabilitation of children with cerebral palsy relieves parents of the ‘burden’ of caring for their children round the clock. It also creates opportunities to parents of participating in community, economic, social and other poverty alleviation activities. Therefore, it was hoped that this study would bring to light problems, difficulties, concerns and fears of parents to better children with cerebral palsy. Many parents are left ill-informed and solely responsible for socially rehabilitating their children. With information generated from this study, it is hoped that better ways and means of effecting social rehabilitation in societies can be formulated. Such knowledge can help in planning rehabilitation services and also serve as a guide in devising strategies for assisting parents better cope with the challenges of bringing up children with cerebral palsy in particular.
The point of departure of this study is the focus on parents and not the disabled children, an approach that many studies overlook. It is therefore, hoped that Organisations in charge of community rehabilitation programmes and donor agencies supporting rehabilitation as well as government institutions may draw information from the results of such studies in coming up with intervention programmes that would best respond to the needs of parents. Consequently, this study is important for parents in recognising the challenges of social rehabilitation and maybe together urge planners, policy makers, aid workers, and the rest of society in finding lasting solutions to the difficulties of rehabilitation.
CHAPTER TWO
LITERATURE REVIEW

The literature presented here centres on studies which focus on disability and parenting taking into account gender differences in rehabilitation practice. Some previous studies carried out on parents of children with special needs focus on mothers. For example in England, Hewitt (1979) conducted a study of mothers of cerebral palsy children aged seven years in their homes. Results indicated that mothers sometimes expect instant development from rehabilitation programmes. For instance, a mother would expect that their child would be able to walk just after a few sessions of physiotherapy.

Hewitt's study unfortunately left out fathers. Parenting is a responsibility of both parents. Essential to the strength of Hewitt's study would have been the inclusion of male parents, a weakness that the present study attempted to build on.

Gruber and Williams (1967) carried out a study in eight South Wales special schools in England. The study was aimed at determining characteristics that differentiate children who respond well to special school education from those who respond poorly. Data was collected by examining children's response to special schooling, file data and visiting the children and their parents in their homes. Results indicated that there was a negative relationship between social class and success. It was also revealed that of the two special groups of children that were selected, the less intelligent (referred to as E group)
tended to consist of children with more organic damage and that the more intelligent (S) group tended to consist of children who showed more environmental impoverishment.

Although the focus of the present study was not on the intelligence of disabled children, special school education is considered as rehabilitation. Therefore, Gruber and William's literature presented above is relevant to parents facing challenges in sending children to special schools or rehabilitation. It helps parents understand that being in a poor environment should not prevent them from engaging their children in rehabilitation. Evidence from Gruber and Williams' study indicate that social class does not influence success. Above all it was observed that, environmental factors where the child comes from do not affect the intelligence of the child.

The methodology used in collecting data from parents in their homes was similar to the present study's. However, the difference is that this study focused on cerebral palsy children and was not comparing the children to any other group. Every individual is unique, and the severity of each disability varies. Therefore, comparisons especially in disabled children may render one child to be less capable than the others and this can be a disadvantage to some children in question. Parents may prefer to favour the more capable child.

Levitt (1988) conducted a medical anthropological study on health beliefs and practices of participants in a community-based programme in St. Catherine,
Jamaica. Results indicated that parents’ views, beliefs and expectations of their children with special needs might delay the seeking of advice or discourage the implementation of an intervention or rehabilitation programme (ibid: 1988). Evidence from levitt’s study also revealed that parents from poorer classes had strong beliefs in the power of God and expected God to change or affect the development of the child with special needs (ibid, 1988).

Similarly, the present study explored parents from different classes for their rehabilitation expectations of their children. However, the difference was that unlike Levitt’s study, which grouped parents’ responses together, the present study disaggregated data between female and male parents’ views, depending on their gender.

However, Munachonga’s work did not take into account children with special needs. It focused on socio-historical and gender stereotypical behaviour in families in general. He observed that in a family, parents are expected to play different roles depending on the sex or gender of the parent. Further, it was noted that gender and gender role-playing in Zambia emphasises the negative impact that socio–historical and contemporary forces have had on women compared to men. Munachonga further observed that gender inequalities in the Zambian society are explained partly in terms of colonial policies, which discriminated against women and partly in terms of traditional, social and cultural norms and practices, which persist in modern urban society.
However, Munachonga's work focussed on socio – historical and colonial policies in general. Such policies may not reflect the economic and social obstacles that influence the gender roles performed by female and male parents. For example, in an urban setting, gender roles performed by female parents may not necessarily be similar to those performed by male parents especially when it relates to rehabilitation.

The United Nations Human Development Report (1990) observed that there were variations in the way women and men spent their time by region, historical period, and even within a country, between rural and urban areas. For instance it was estimated that two thirds of all housework was performed by women, with women spending up to thirty hours or more on housework each week, while men spent around ten to fifteen hours per week. Studies in the 1990s in countries like Britain, Canada, America and Finland showed that while the division of labour remained firm in these countries, with women engaged in tasks of laundry, cleaning the home, child-rearing and preparation of food, it was also observed that there had been a decline in the burden of work and time spent doing the paid and unpaid work for both women and men.

The decline in burden of work was reported to be achieved by the improved technologies in appliances like, washing machines, hovers, microwave ovens, and blenders to mention but a few. These machines helped in food processing and many other tasks in industrialised countries. These technologies contribute in easing the work and time spent accomplishing the
tasks in the home. In addition women and men in industrialised countries are able to buy consumer goods and services that already incorporate many of the earlier stages of food preparation, whilst most women in developing regions of Africa and Latin America have to perform the tasks of collecting firewood, grinding, collecting water and cooking by themselves. (op.cit,1990).

Ingstad and Whyte (1995) carried out a case study on experiences of children in rehabilitation institutions in Botswana. Results revealed that mothers feared that their children would be abused in institutional rehabilitation centres. Parents further feared that their children wouldn't be cared for in institutional rehabilitation with the same intensity and care as in the home. They also revealed that one mother discovered that her son suffered abuse by having his teeth forcibly removed. When queried, staff at the institution explained that the boy used to bite his colleagues and therefore to prevent him from biting his friends, his teeth had to be removed.

Morgan (1984) revealed that the abuse of children is a woman's problem because it is usually the female children who are abused nutritionally, sexually, and psychologically. Much as these reasons are positive concerns, and may justify parents' concerns, it should be born in mind that male children are also victims of certain forms of abuse. In tandem with Morgan's discovery, Ingstad and Whyte referred to above, also observed that such fears were not without ground because often times parents' fears turn out to be real. However, such revelations unless checked may instil insecurity in many parents. Parents of disabled children would not be encouraged to send their
children for institutional rehabilitation. Although this case may be an isolated one, there maybe other experiences that pose a challenge to parents.

In Zambia, there had been research carried out on disability. For instance, Serpell (1982) conducted a study on parents of children with disabilities in a rural society in eastern province of Zambia. Serpell’s study explored the needs and aspirations of the children. He argued that an individual child should be assessed in order to offer her or him an appropriate education at which development programmes must be aimed. Serpell asked parents to define the respective roles at home and school in their child’s socialization. Results revealed that most of the parents emphasized the skills of literacy and numeracy as the most important attributes they expected their child to learn from school. It appeared that most parents seemed to be concerned about their children being able to read and write even when that might not be the best thing for the child to achieve. This viewpoint is similar to results showed by parents’ responses in the present study. However, whereas Serpell’s study emphasised needs and aspirations of the children, the present study focused on the challenges of the parents. Instead of a rural population, the inquiry was conducted in an urban setting.

Kasonde-Ng’andu (1986) conducted a study on aspects of upbringing and education of sixteen children with special educational needs in a rural Bemba culture in Zambia. Results revealed that superstitions, beliefs and social problems such as transport were some of the challenges that led most parents to prefer rehabilitation that takes place in the home environment. It
was also indicated that a number of parents had low expectations of their children. This was based on observation of the way the child behaved and carried out some of the tasks. Kasonde-Ng'andu's study also found that most parents believed in witchcraft as a major cause of disability in children. Other factors that Kasonde-Ng'andu identified as an influence in rehabilitation were poverty, and education of parents. It was discovered that educated parents were more in support of formal educational rehabilitation than social rehabilitation in the child's environment.

Similarly, this study attempted to investigate the relationship of social status and education on rehabilitation. However, whereas Kasonde-Ng'andu examined only sixteen children with special educational needs in a rural area, the present study investigated a larger sample and on an urban population. Additionally, religion and gender differences of parents' challenges and actions of rehabilitation were investigated in the present study. In rural areas, social status of individuals is usually similar; therefore, comparing parents in such a setting does not yield a pattern that can reveal significant differences in the characteristics of parents.

Foss and Siakonomba (1985) observed that rehabilitation of disabled individuals indicates that boys more than girls are the target of rehabilitation. Results from their study carried out at the Ndola vocational rehabilitation centre, revealed that out of forty (40) students that were enrolled at the centre, only ten (10) were women, and the rest were men. This led them to conclude that rehabilitation is more targeted at men.
Consequently, there is a problem in drawing the above assertion that rehabilitation is targeted at men. Such a conclusion may leave out other contributing factors that hinder parents engaging their children in rehabilitation such as the problems of parenting and care.

In addition to the above, the Zambia Central Statistical Office (ZCSO, 1990), the Ministry of Education (MoE, 1996) also observed the gender imbalances in schools. For example, results from the 1990 census report indicated that there were more boys in educational rehabilitation than girls. Out of 11,000 disabled children recorded in the age group 7-13 and school going category, 54% were boys and 46% were girls Zambia Central Statistical Office (2000).

Although the present study also considered the proportion of girl children to that of boys, the focus was not on the numbers but mainly the biases that are involved in rehabilitation. The above picture may be indicative of the fact that parents may be choosing to send more boy children to rehabilitation than girl children. Realisation of such a reality is important in aiding to come up with inclusive strategies of rehabilitation that are gender sensitive in terms of providing for the needs of both male and female parents and their children regardless of gender differences.

In 1985, for example the International Decade for Disabled Persons (IDD) emphasized great awareness of the needs of the disabled in their environments without calling attention to the awareness of the challenges that carers or parents of the disabled face in raising them. Such an approach
seems to be based on the assumption that since there exists a few rehabilitation centres in urban areas, urban parents of children with disabilities may need no further support.

The Zambian Ministry of Education (1996) and Ministry of labour and Social Services (MoLSS) carried out a campaign to reach disabled children from 1980 to 1985 in Zambia. This was aimed at raising the consciousness of the special needs of the disabled and to establish comprehensive registers as well as supply technical aids and lay foundation of nation-wide health and educational services for disabled children. It was revealed that prevalence of serious disability in children aged 5-15 for the ten urban districts in the study, as a group of the actual registered prevalence was 4.0 per 1000 (ZNCRDC Report, 1985).

Conclusion

From the review of literature above, it has been demonstrated that much of what has been studied on disabled children have concentrated on either children or the disabled in general and have tended to neglect the need to explore the lived experiences of parents in general. The point of departure for the present study is that it looks at children with cerebral palsy specifically. Literature for the present study has also attempted to highlight the gender dimension by trying to disaggregate data on the basis of sex of parents.
CHAPTER THREE

METHODOLOGY

In this chapter, the methods used to collect data are presented. The chapter begins with the study design, population of the study and description of the pilot study carried out prior to the main study. This is followed by the main study and ends with problems encountered in data collection.

3.2 Design
The study employed the survey method in data collection to sample cases from varied backgrounds. Although cases were drawn from two institutions, the distribution was done across all areas in the study site and on a small scale. This method was chosen to allow for easy identification of cases.

3.3 Population
The population comprised all parents in Ndola urban of children with Cerebral Palsy. According to the 2000 census of population and housing, out of a total population of 1,527,294 people resident on the Copperbelt province, 2.3 percent were disabled (ZCSO, 2000). The number of persons resident in the urban part of the province was 1,236,570. The rationale for choosing Ndola urban was because, out of all the Copperbelt towns, Ndola seemed to have more rehabilitation services. It was therefore felt that if challenges of rehabilitation existed in an area that had a number of rehabilitation services, then how much more social rehabilitation challenges would parents in areas that have few rehabilitation services experience. As a consequence,
experiences and expectations of parents would therefore add new knowledge to the existing limited body of knowledge on parents’ challenges.

3.4 The Sample and Sampling Procedure

The sample consisted of fifty parents drawn from schools and hospital records in Ndola urban. Out of the fifty parents who were sampled, only thirty-three parents were present to participate in the study. Of the thirty-three, twenty-three were female and only ten were male because most male parents could not be found at home even after repeated visits. Cases of Cerebral Palsy are not easily identifiable. Even in established special educational institutions, children are not recorded by type of disability. One of the difficulties indicated was that diagnosis of Cerebral Palsy is rarely carried out or indicated to the parents. This is because it is a condition that does not fit neatly in one classification.

Two types of sampling methods were therefore employed. That of stratified sampling (divided into groups) and the snowball (research by the word of mouth) method of sampling. Firstly, the stratified method was employed in selecting schools and institutions from which children with this condition could be drawn. The children’s parents were respondents for the study. Interest in focusing on the parents and not the children stemmed from the researcher’s personal experienced of raising and in the process, trying to rehabilitate a child with cerebral palsy in Ndola urban. Parents were sampled using the children’s records. However, this proved to be problematic in that in certain instances it was not possible to know whether the parent was single, married
or a guardian. The assumption made was that every child had both parents, which would afford the researcher to interview 50 parents. The approach was to have an equal representation of parents by gender. However, this could not be achieved because of the reason mentioned above; notably parents not being found at their various locations. Ndola urban had an estimated number of six established rehabilitation centres. Of the six, two were selected. Therefore, respondents came from Kansenshi Basic School and Arthur Davison Children’s Hospital Physiotherapy Department.

The selection of these two institutions was based on the recommendation of the Ministry of Education and the Ndola District Health Management team who indicated that the two were well established and would give a fair representation of parents from all areas. In addition the focus of the study was to get parents of children in the age group between six months and twelve years. These were the institutions that were indicated to have children in that age group. The location of the two institutions was another determining factor that was taken into consideration. Kansenshi Basic School is situated in the high-class residential area surrounded by households of Northrise, Central Business District (CBD) and Hillcrest. Arthur Davison Hospital on the other hand is closer to the peri-urban compounds of Sinya, Chipulukusu, and Pamodzi townships.

From each of the two institutions simple random sampling was used. The intention was to select an equal representation of female and male parents. However, it turned out that a few children were being looked after by
guardians. Numbers were assigned to the names of children. The simple random sampling method on the list of children was used to pick cases of cerebral palsy children. Female and male children were listed separately and then every fourth child on the list was picked. This was done to allow an equal chance of every child to be picked in the sample.

3.5 Research Instruments

Data collection was carried out through questionnaires using semi-structured interviews. Each questionnaire consisted of four parts. The first part had introductory remarks, identification codes and locations. This was followed by information on personal characteristics of the parent such as age, sex, occupation, educational level attained and income. The third part was on the child’s characteristics, gender roles and challenges. The last part centred on expectations of parents and recommendations. Interviews have an advantage of allowing both the respondent and the interviewer to seek clarification on issues that may not be clear. However the disadvantage is that sometimes individuals do not give honest answers because it involves face to face interviewing which does not allow for anonymity.

3.6 Pre-Testing of Research Instruments

Pre-testing of instruments was carried out in the Kalewa Army Barracks in Ndola on the Copperbelt Province of Zambia from 1-7th August 1999. Pre-testing of the instrument was conducted by interviewing only two families. The rationale of involving only two families was that cases of cerebral palsy were difficult to identify. Therefore, it was felt that if more families were involved in the pre-test, there would be fewer cases to incorporate in the main study.
Moreover, the two families were the first cases of parents with children of cerebral palsy in Ndola that the researcher came across. The two families were picked using the snowball method of sampling. This method was employed while waiting for the lists of names of children with cerebral palsy from Arthur Davison Hospital physiotherapy department and Kansenshi Basic school- special unit.

The purposes of pre-testing the instruments were:

1. To examine whether or not parents would easily and clearly comprehend the questions in the questionnaire both in the pre-test and more so in the main study.

2. To determine how receptive and comfortable parents would be in being interviewed in their homes.

3. To have an idea of whether it would be difficult to find parents and children of that nature.

At the end of the pilot study, the researcher realised that some of the questions were a repetition and therefore, needed to be removed. The word rehabilitation was not clearly understood and needed to be translated into Bemba when interviewing (Bemba is the most predominantly spoken language in Ndola). The researcher was therefore, translating the term into Bemba during the interviewing process. Other than that, parents seemed to have clearly understood the questions.
3.7 Data Collection Procedure

There was a slight shift in the procedure from the one used in the pre-test. This was because some parents had to be interviewed at rehabilitation centres unlike in the pre-test where both couples were interviewed in their homes. This was because some parents refused to be followed in their homes. However, in both the pre-test and the main study, the methods of observation and interview by questionnaire were used.

3.8 The Research Site - The Case of Ndola Urban

The study was conducted among families who had children with cerebral palsy in Ndola urban. Ndola is the second largest town in Zambia and is the provincial capital of the Copperbelt province. It also used to be Zambia's industrial capital town. Many big and strategic industries of the country used to be found in Ndola before the liberalisation of the economy. It is speculated that competition with foreign firms that had advantages over local producers forced many industries to close down. Ndola town used to be the gateway to the Copperbelt.

Before the Government adopted the Structural Adjustment Programme (SAP) and its subsequent implementation, most people in the town of Ndola were working in the mines and the various industries and companies that existed in the town. The town being the industrial centre of the country had a large workforce, employed in the industries and other supporting companies. Hence many people had means of earning an income or were in wage employment prior to SAP.
Circumstances changed with the adoption and the subsequent implementation of the Structural Adjustment Programme. These programmes were accompanied by privatisation programmes, removal of subsidies, wage rise restraint, retrenchments, restructuring of government ministries, closure and liquidation of companies that were seen not to be making profit (Kelly, 1996).

The mines were closed before privatisation and so were some of the other companies, which were state owned. This resulted in major loses of employment among the people of Ndola and elsewhere where the programme was affected. Poverty was therefore entrenched deeply in the towns where the companies were closed. For example, during the period of 1991-1996, the town of Ndola had 176,000 incidences of poor persons in the urban areas. This was about 44.7% of the poor persons in the town (ZCSO, 1998). The case was even higher in Ndola rural where poverty levels were as high as 84.9%. It was also further noted that there were high incidences of households whose heads of the house had left the last job or business because the firm they were working for was privatised (57.9%), liquidated (53.3%) or failed to make a profit (53.6%). These statistics, however, represented the whole country as statistics for districts or individual towns were not collected (Ibid: 1998)
However, the current picture of poverty on the Copperbelt province of Zambia under which Ndola, the study site, falls represents the following:

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely Poor</td>
<td>38%</td>
</tr>
<tr>
<td>Moderately Poor</td>
<td>20%</td>
</tr>
<tr>
<td>Total Poor</td>
<td>58%</td>
</tr>
<tr>
<td>Non-Poor</td>
<td>42%</td>
</tr>
</tbody>
</table>

The above figures are derived from a total population of 1,707,843 for the Copperbelt province, (ZCSO, 2004). Further, it was reported that one in every three persons in urban areas at 32 percent was living in extreme poverty (Ibid 2004). This information is important in presenting the economic status of parents as it may be related to rehabilitation.

In Ndola, rehabilitation programmes were introduced much later in 1998 when the Catholic Diocese in conjunction with some Non-Governmental Organisations (NGOs) introduced community based rehabilitation programmes in the following centres namely; Chifubu, Chipulukusu, Mushili, Sinya and Twapia. In spite of these programmes, not much impact has been made on rehabilitating children. Many parents seem not to be aware of these rehabilitation facilities.

Consequently, special units introduced in primary schools in Ndola, exhibit the same pattern as that in the capital city of Zambia where severely affected children are not catered for. According to The Ministry of Education, there are eight (8) primary schools with special units in Ndola. Two (2) missionary-run
rehabilitation centres, namely Holy Family School for disabled children up to the age of eleven (11) and the Cheshire Home in Kansenshi residential area, which is a residential school/home that only takes on children from the age of fourteen (14) years old.

3.9 Data Collection

A combination of methods to collect data such as face to face interviews with the parents who had children with cerebral palsy, survey methods in which questionnaires were used and secondary data review. A pre-test was also carried out before embarking on a full-fledged study. The major thrust of the study was as given in the statement of the problem below.

Parents in the study were drawn from an urban population of Ndola covering low, medium and high-density residential areas. The rationale for concentrating on an urban population was that most research in this field has been on rural populations. Statistics indicate that there are more disabilities in rural areas 3.2 percent than urban areas 2 percent (ZCSO, 2000). However, due to the difficulties experienced in finding children specifically diagnosed as children with cerebral palsy, all children whose disability was considered a result of the known causes of cerebral palsy (some of which were cerebral malaria and/or meningitis to mention a few were included in the study).

Closed ended and open-ended questionnaire and semi-structured interviews were used. The study was therefore based on both qualitative and quantitative methods. In collecting secondary data the following resource
centres were visited: Zambia Institute of Special Education (ZAMISE), UNICEF library, Institute of Economic and Social Research Library (INESOR), Zambia Association for Research Development (ZARD) library, ILO, Zambia Association for Children with Learning Disabilities and the University of Zambia main library at Great East Road campus and the Medical Library situated at the University Teaching Hospital (UTH) premises. Data was analysed both manually and using the Statistical Package for Social Science (SPSS). The t-test was also used in verifying the validity of the conclusions.

3.10 Data Analysis
The t-test is one of the parametric tests that require making assumptions about the population parameters. For it to be performed, it requires that conditions of random sampling and a relatively large sample size, normal distribution and the level of measurement are met. All these conditions were met before the tests could be applied in this study. In using the t-test, the critical values formed the boundary line between the acceptable and non-acceptable values. The computer software; SPSS was used in computing the t-test.

3.11 Data Interpretation
After computing the test and comparing them with the critical values, some hypotheses were rejected while others were accepted. Responses from interviews were coded and grouped to establish common themes. Thereafter, frequencies and percentages were calculated. The analysed data was presented in form of tables. The t-test was used to compare significance of
differences between the two groups of female and male respondents and also as another method of making inferences.

3.12 Limitations of the Study

There were a number of problems that were encountered during the process of data collection both during the pilot study and the main study. Firstly, the two couples were drawn from one residential area. This entailed that conclusion of what could be expected in the main study were limited to one location. The fact that the two couples were drawn from one residential area was a disadvantage. It limited a chance to determine what was expected of parents from other areas in a different social class. However the rationale for using only one locality was arrived at after considering the limited number of known cases of cerebral palsy. It was anticipated that there would be very limited cases for the main study if a bigger group in the pilot study was selected.

The main study had four major limitations. Firstly, transport was a problem. The geographical position of the homes of the parents also posed a problem. Other hurdles were that it was difficult to find the house numbers in the compounds since most of the houses were not numbered. This entailed a lot of walking. Some families had moved from locations known or indicated to registered rehabilitation centres. One parent had given a false house number and address of a relative. In this case, following up such respondents proved futile. The other major problem was of finding male parents at their homes.
Two male parents could not be interviewed because they were not found at their homes, even after making repetitive appointments and visits with their wives. One male parent simply refused to be interviewed. Consequently, fewer male parents than female were interviewed giving an imbalance in the number of parents interviewed by gender. Unfortunately two children had died without the knowledge of the staff at the centre where the list was obtained. This was because the list of names of children provided was never updated for several years.

The second problem was that records of background information on each child were not readily available. This is because assessment in Zambia is problematic, a good number of children have never been assessed. The Head of special unit also explained that children's conditions were not specified in the register. Children were recorded simply as 'slow learner', 'dumb- speech impaired', 'deaf – hearing impaired', or retarded. It was explained that this was because when parents took their children to be enrolled they simply mentioned any of the above listed categories. This was however not surprising as existing literature indicates that diagnosis of cerebral palsy in Zambia and the world over is a problem because cerebral palsy is a condition that does not fit neatly in one classification. It is common for an individual with cerebral palsy to present multiple disabilities. For instance, one can be physically disabled, have speech impairment and hard of hearing at the same time. For such an individual one cannot simply state that the individual is physically disabled or has speech impairment.
Information on children's conditions would have been helpful in coming up with cases likely to fall in the category of cerebral palsy. Available literature indicate that cerebral palsy is usually as a result of cases such as cerebral malaria, jaundice, meningitis, premature birth, cord strangulation at birth but to mention a few (Kapulisa, 1981). The third problem was that the Headmaster refused to divulge any information on the children without a letter from the Ministry of Education authorising him to allow the researcher to carry out the study at that school. Despite producing a letter of introduction from the University of Zambia, the Headmaster could not give consent, until a letter was obtained from the Ministry of Education. The letter enabled the researcher to have access to information pertaining to disabled children. Unfortunately, children were on school holidays, therefore, contacting the parents in their various homes proved difficult.

At each of the two institutions, children whose disability fitted that of cerebral palsy were selected. The sample was randomly selected, although the occurrence of cerebral palsy is random in itself. Selection of children with cerebral palsy was also done with the help of the special teachers. Not all the schools were visited by the researcher because, experience with the Kansenshi basic School which was visited first, revealed that out of the fifteen children listed by the class teacher as possible cases of cerebral palsy, only two turned out to be with mild cerebral palsy. Therefore, schools were abandoned as a source of children with cerebral palsy. It was also realised that very few special schools in Zambia catered for severely affected children.
CHAPTER FOUR
PRESENTATION OF RESULTS

4.1 INTRODUCTION

Study results from interviews conducted and questionnaires administered to parents of children with cerebral palsy to determine challenges of rehabilitation are presented. The study findings are presented according to the objectives of the study. Sub-themes such as socio-economic factors of sex, age, religion, educational levels and economic status of respondents and other major study results are also presented.

4.2 Social-economic background of Parents

4.2.1 Parents’ age by Sex

The ages of respondents are presented in Table 1 below.

Table 1: Age in years of Parents by Sex of Parent

<table>
<thead>
<tr>
<th>Age in yrs</th>
<th>Female Frequency</th>
<th>Female %</th>
<th>Male Frequency</th>
<th>Male %</th>
<th>Total Frequency</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 - 25</td>
<td>2</td>
<td>8.7</td>
<td>2</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25 - 35</td>
<td>13</td>
<td>56.5</td>
<td>5</td>
<td>50</td>
<td>18</td>
<td>54.5</td>
</tr>
<tr>
<td>35 - 45</td>
<td>6</td>
<td>26.1</td>
<td>5</td>
<td>50</td>
<td>11</td>
<td>33.3</td>
</tr>
<tr>
<td>Above 45</td>
<td>2</td>
<td>8.7</td>
<td>2</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>100.0</td>
<td>10</td>
<td>100</td>
<td>33</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: Field Data

The majority of parents were in the age group 25-35. In this age group, there were a total of 8 (54.5%) parents representing 13 (56.5%) females and 5 (50.0%) male parents. This was followed by the age group 35-45 years, a total of 11 (33.3%) parents. Females accounted for 6 (26.1%) and 5 (50.0%) male parents.
4.2.2. Distribution of Parents in the Study

**Figure 1: Parents by Sex**

The sex of the respondents was analysed and presented pictorially (Figure 1)
n=33

![Pie chart showing sex distribution among respondents (30% Male, 70% Female)](image)

*Source: Field Data*

There were more female parents 70% than male parents 30% in the study as represented in the pie chart above. It was revealed that respondents' residences were drawn from low cost areas or high-density areas 69.7%, medium density areas 15.2% and high cost or low-density areas 15.2%. All the respondents were from Ndola urban.
4.2.3 Parents' Marital Status

Table 2: Marital Status of parents by Sex

The marital status of the respondents was categorised and tabulated (Table 2).

<table>
<thead>
<tr>
<th>Martial Status</th>
<th>Female Frequency</th>
<th>%</th>
<th>Male Frequency</th>
<th>%</th>
<th>Total Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>19</td>
<td>82.6</td>
<td>10</td>
<td>100</td>
<td>29</td>
<td>87.9</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>13.0</td>
<td>10</td>
<td>100</td>
<td>3</td>
<td>9.1</td>
</tr>
<tr>
<td>Single</td>
<td>23</td>
<td>0.0</td>
<td>10</td>
<td>100</td>
<td>33</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: Field Data

Most parents were married 29 (87.9%). All the male respondents were married 10 (100%), compared to 19 (82.6%) female respondents. Amongst the female parents, (3) 13% were widowed and (1) 4.3% were single parents.

4.2.3 Relationship of Respondents to the Children

The respondents' relationship to the children was analysed and tabulated.

Figure 2: Relationship of Respondents to the Children

Source: Field data
Respondents were related to children as mothers (60%), fathers (34.3%) and step father/mother (2.9%) or as Grandparent (2.9%). Grandparents were referred to as guardians in the study. Besides having children with cerebral palsy, many parents had other children such as siblings to the disabled children (88.6%). Only a few parents did not have other children (1.4%).

4.2.4 Position of the children with Cerebral Palsy in the Family

The position of the children with Cerebral Palsy in the family (whether as a first-born or otherwise) tends to have very profound influence on their rehabilitation, on parents and on siblings’ mental health. There were 22.9% of the parents who had first-born children with Cerebral Palsy. Second born children with cerebral palsy accounted for 31.4% and the rest were third, fourth and even fifth positions.

4.2.5 Number of Children by Sex of Parent

Table 3: Number of children by Sex of Parent

n=33

<table>
<thead>
<tr>
<th>How many children</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>1 – 3</td>
<td>17.4%</td>
<td>10.0%</td>
</tr>
<tr>
<td>1 – 3</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>4 – 6</td>
<td>30.4%</td>
<td>30.0%</td>
</tr>
<tr>
<td>4 – 6</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>7 – 9</td>
<td>39.1%</td>
<td>30.0%</td>
</tr>
<tr>
<td>7 – 9</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>More than 10</td>
<td>8.7%</td>
<td>10.0%</td>
</tr>
<tr>
<td>More than 10</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Field Data
Most parents had four to six children. The highest category of number of children was the four to six categories and this accounted for (36.4%) of the parents with this number of children. Only 3 (9.1%) of parents had more than ten children. Approximately 5 (15%) indicated that they did not have children. These were most likely guardians to the children.

4.2.6 Religion of Respondents by Sex

![Image of a bar chart showing percentages of Religion of Respondents with Catholics at 39.4%, Protestants at 27.3%, Watch Tower at 3.0%, and Other Churches at 30.3%]

**Source:** Field Data

All the respondents in the study were Christians. Prominent among the denominations were the Catholics representing 13 (39.4%) of the respondents. The rest belonged to Protestants 9 (27.3%), Watch Tower 1 (3.0%) and other churches 33 (30.3%) comprised the Reformed Church in Zambia, Anglican Church, Pentecostal Holiness and the Apostolic faith mission grouped together.
4.2.7 Educational Level of Respondents

The education level of the parents was generally low. For instance, many of the parents had education up to grade seven 7 or below 15 (45.5%). Distributed by gender, there were 12 (52.2%) females and 3 (30%) males. However, 7 (21.2%) had reached secondary school while 4 (17.4%) females and 2 (20%) males had college certificates. Only 1 (4.3%) female was a University graduate.

4.2.8 Monthly Income

<table>
<thead>
<tr>
<th>Monthly Income by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Below K100,000</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>K101,000 - K200,000</td>
<td>60.9%</td>
<td>40.0%</td>
</tr>
<tr>
<td>K201,000 - K400,000</td>
<td>21.7%</td>
<td>30.0%</td>
</tr>
<tr>
<td>K401,000 - K600,000</td>
<td>13.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>K601,000 - K800,000</td>
<td>4.4%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data
The findings revealed that 14 (60.9%) women earned amounts that were less or equal to K100, 000 per month compared to 4 (40.0%) men earning the same amount. Women earned incomes far less than those that men earned. The highest earnings amongst the women were K400, 000 per month while it was K800, 000 per month for men. Women as a group earned considerably less than their male counter parts.

4.2.9 Occupation of Parents

Table 5: Parents Occupation by Sex

n=33

<table>
<thead>
<tr>
<th>Parents Occupation by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Formal employment</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>17.4%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Self employed</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>73.9%</td>
<td>10.0%</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>8.7%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data

Formal employment represented 9 (27.3%) of parents, comprising of 4 (17.4%) of females and 5 (50%) of males. There were 9 (30%) of male respondents who were self employed. Surprisingly, there were no female respondents who indicated that they were self-employed.
Most of the parents in the study had no sources of income 18 (54.5%). This was still highly dominated by women, as 17 (73.9%) of women did not indicate any occupation compared to only 1 (10%) men in the same bracket. As indicated above, there were no female respondents that indicated that they were self-employed. On the other hand, there were 30% of males who were self-employed. Formal employment comprised 4 (17.4%) of females and 5 (50%) of males making up a total of 9 (27.3%).

4.3 Parents and Challenges

Table 6: Whether parents faced challenges by Sex of Parent

<table>
<thead>
<tr>
<th>Parents problems by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Do you face any problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>91.30%</td>
<td>70.0%</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4.35%</td>
<td>30.0%</td>
</tr>
<tr>
<td>No opinion</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.35%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data
When parents were asked whether they faced challenges of rehabilitation or not by gender, female parents 21 (91.3%) indicated facing problems than male parents 7 (70%). Only 1 (4.3%) of the female parents expressed that they did not face any challenges. Interestingly, there was 1 (4.3%) of the female respondents who had no opinion on whether they faced challenges or not. There were no male respondents who had no opinion.

### 4.3.1 Specific Challenges by gender

**Table 7: Parents Challenges by Sex**

n=33

<table>
<thead>
<tr>
<th>If Yes, What challenges by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Feeding</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>8.7%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Dressing</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td></td>
</tr>
<tr>
<td>Medical Attention</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td></td>
</tr>
<tr>
<td>Mobility to various place</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>47.8%</td>
<td>40.0%</td>
</tr>
<tr>
<td>Difficulty to establish his/her needs</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>N/A</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data

Respondents were asked to specify what challenges of rehabilitation they were facing with their children with Cerebral Palsy. The above results showed that the greatest challenge was that of mobility 15 (45.5%). Both female 11 (47.8 %) and males 4 (40%) bemoaned the difficulty of mobility for their children in rehabilitation. The other challenge was the difficulty of parents to establish what their child’s needs were, 3 (13%) for females and 2 (20%) for males.
4.3.2 Parents’ Responses

Table 8: Parents responses to the rehabilitation needs of their Children by Sex

<table>
<thead>
<tr>
<th>What are the responses by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Give adequate attention</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>8.70%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Teach him how to walk, talk, feed and going to toilet</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>21.74%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Help from other people</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>17.39%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Physiotherapy/exercise</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>17.39%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>21.74%</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>13.04%</td>
<td>10.0%</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data

Table 5 on the previous page indicates that out of thirty-three respondents, 5 (21.7%) females and 3 (30%) males considered teaching the children how to walk, talk, feed and go to toilet on their own, as the most important response to their children’s needs. The least indicated response was giving attention to the children.

4.3.3 Parents’ worries

n=33

Source: Field data
Parents were asked what their worries were about their children. Findings revealed that most parents 14 (42.4%) worried about their child’s life or simply well-being. The gender desegregation of the findings here revealed that there were (10) 43.5% female parents and 4 (40%) males with that worry.

Of all the parents who responded to this question, 9 (27.3%) expressed that they would worry about the future of their children. Results also revealed that 2 (20%) of the male parents were worried about who would look after their children if they died as compared to 2 (8.7%) of the female respondents. Further, 2 (6.1%) of parents (both male and female) expressed worry about their children’s welfare and had anxieties about other aspects of the children’s life.

4.3.4 Gender of Children by Parents’ Sex

n=33

| Figure 7: Gender of children by sex of parents |
|---|---|
| Yes | 6% |
| No | 91% |
| No opinion | 3% |

Source: Field Data
Respondents were asked on whether the sex (biological makeup of child-boy or girl) of their children would spell different challenges to them. Results showed that most parents 87.9% believed that the sex of the child would not spell different challenges to them. From a gender perspective, female respondents 21 (93.3%) believed that sex of the child had no relationship to type of challenge. Male parents who responded in the same manner represented 8 (80%).

4.3.5 Difference of child’s gender by sex of parent

Table 9: If gender of child spelt different challenge by sex of parent

<table>
<thead>
<tr>
<th>If Yes, why do you say so</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Problems are the same</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td>Both (boy/girl) are children</td>
<td>1</td>
<td>4.35%</td>
</tr>
<tr>
<td>N/A</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>91.3%</td>
<td>90.0%</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4.35%</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Field Data

Parents who indicated that the gender of the child would not spell any difference in challenges were further probed why they thought so. Responses from males pointed to the fact that problems that parents encountered with the children were the same 1 (3.0%). Male parents responded to this question. Females on the other hand stated that children were the same regardless of their gender 1 (4.3%). The majority of the parents could not give reasons for their position 21 (91.3%) females and 9 (90%) male parents or 90.9% for both females and males.
4.3.6 Feeding by Sex of Parent

Table 10: Parents’ challenge of feeding by Sex of Parent

n=33

<table>
<thead>
<tr>
<th>What Challenges-Feeding</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>None</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>43.5%</td>
<td>40.0%</td>
</tr>
<tr>
<td>Refuses to eat</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4.3%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Can’t swallow/eat on his own</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>17.4%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Irregular food supply</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>21.7%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>8.7%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data

Asked on the challenges parents faced with their children with cerebral palsy, the majority said that they faced irregular food supply, which could be attributed to the poor performance of the economy. Other respondents said their children had problems of swallowing and could not eat on their own. Only 1 (4.3%) and 1 (10.0%) male said their children refuse to eat.

4.3.7 Action by Sex of Parent

Table 11: What action taken for rehabilitation by sex of parent

n=33

<table>
<thead>
<tr>
<th>What action do you take</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>21.7%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Teach him</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>34.8%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Provide more food/liquid</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>17.4%</td>
<td>10.0%</td>
</tr>
<tr>
<td>N/A</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>8.7%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data
Respondents were asked on the remedial measures they carried out to ensure rehabilitation of their children. The majority of the respondents said they taught their children to eat. Unfortunately, some respondents 5 (21.7%) females and 3 (30%) males responded that they took no action.

4.3.8 Expectations by Sex of Parent

Table 12: Expectations of Parents by Sex

n=33

<table>
<thead>
<tr>
<th>Who do you expect by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Mother</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Father</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Grand Parents</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Maid</td>
<td>4.35%</td>
<td></td>
</tr>
<tr>
<td>Siblings</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No one</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

Source: Field Data

Respondents were asked to indicate whom they expected to rehabilitate or care for their children with cerebral palsy. Most of the respondents responded that they did not expect help from anyone 18 (54.5%). There were an equal number of respondents who said they either expected the maid or grandmother to help them take care of their children 1 (3.0%) for each category.
4.3.9 Knowledge by Sex

Table 13: Knowledge of the term rehabilitation by Sex

n = 33

<table>
<thead>
<tr>
<th>What do you understand by Rehabilitation</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Repair</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Correct</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Improve</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>12</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td>9.99%</td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Field Data

Respondents were also asked if they understood the meaning of rehabilitation. 16 (48.5%) of the respondents expressed ignorance on the meaning of rehabilitation. An equal percentage of respondents indicated that rehabilitation was to correct or repair 2 (6.1%) from each category.

4.4 Importance of rehabilitation by sex

Table 14: Whether rehabilitation was important for Children by Sex of Parent

n = 33

<table>
<thead>
<tr>
<th>Do you think Rehabilitation is Important</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Do you think</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>22</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>95.7%</td>
<td>100%</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4.3%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Field Data
When respondents were asked on whether they thought rehabilitation was important or not 32 (97%) of the parents said that rehabilitation was important. Only 1 (3.0%) felt that it was not important. All male parents considered rehabilitation to be important 10 (100%) compared to female parents 22 (95.7%). However, both sexes regarded rehabilitation as important.

4.5 Type of Rehabilitation by Sex

Table 15: Type of Rehabilitation by Sex of Parent

n=33

<table>
<thead>
<tr>
<th>If Yes, What Type of Rehabilitation by Sex of Parent</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>26.1%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Schooling</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Daily living activities</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>26.1%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>21.7%</td>
<td>50.0%</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>8.7%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Field Data

When respondents were asked on what type of rehabilitation they wished or expected for their children, 9 (27.3%) of the respondents said they wished their children to go for physiotherapy. 10 (30.3%) indicated other types of rehabilitation. Surprisingly schooling was the last type of rehabilitation parents wanted their children with cerebral palsy to be engaged in.
4.5.1 Place of Rehabilitation by Sex

Table 16: Preferred place of rehabilitation by Sex of Parent

<table>
<thead>
<tr>
<th>Where would you prefer Rehabilitation to take place</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>At home</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>17.4%</td>
<td>20.0%</td>
</tr>
<tr>
<td>In hospital</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>34.8%</td>
<td>40.0%</td>
</tr>
<tr>
<td>At school</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>30.4%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data

The table above addresses the parents’ preferred places of rehabilitation. Most parents 12 (36.4%) preferred the hospital. A number of parents preferred that rehabilitation took place in school 10 (30.3%). (Interestingly, in table 16, no male parent indicated schooling as a type of rehabilitation).

4.5.2 Contribution by Sex

Table 17: Parents’ Contribution to Rehabilitation by Sex

n=33

<table>
<thead>
<tr>
<th>What is your contribution to rehabilitation</th>
<th>Sex of Parent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Nothing</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4.4%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>30.4%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Exercising</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>43.5%</td>
<td>70.0%</td>
</tr>
<tr>
<td>School work only</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>20.0%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8.7%</td>
<td>6.1%</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13.0%</td>
<td>9.1%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Field Data
Respondents were also asked on their contributions towards rehabilitating their children with Cerebral Palsy. Most parents 17 (51.5%) helped their children in exercises where as 2 (24.2%) indicated that they took their children for Physiotherapy.

![Figure 8: Parents' Gender Roles Performed by Sex](image)

Source: Field Data

5.2.1 Age and Sex of Respondents

Asked on the tasks that parents do with their children, most of the respondents 15 (45.5%) indicated that they did other kind of activities with their children, while 11 (33.3%) walked with the children. At least 4 (12.1%) of the respondents said they watched Television with their children and only 1 (3.0%) said they did gardening with the children.
CHAPTER FIVE
DISCUSSION OF RESULTS

5.1 INTRODUCTION

Characteristics of parents and children with cerebral palsy are discussed. The chapter also addresses challenges faced by parents in rehabilitating children with cerebral palsy. Factors influencing parents in rehabilitation such as gender bias and gender roles are also discussed. Issues surrounding how parents respond to rehabilitation needs of their children are outlined. The chapter ends with a discussion on information that can benefit programme managers and policy makers regarding social rehabilitation.

5.2 Socio-Economic Background of Respondents

5.2.1 Age and Sex of Respondents

Age and sex of respondents are a factor both in cases of younger mothers and older ones. In the case of younger mothers, they have higher chances of having a stillborn child, are likely to experience obstetrical complications and to die during child birth due to limited capacity to sustain a healthy embryo (Shaffer, 1985). On the other hand, mothers older than thirty-five years also face extra risks of obstetrical problems. These, especially first timers, are more likely than women in their twenties to have complications during pregnancy, to have longer and more difficult labour and to deliver infants who are small, premature, or stillborn or who show signs of any of the varieties of congenital defects. This is of particular relevance to the study, because as indicated earlier in previous chapters, some of the causes of Cerebral Palsy
were premature birth and difficult labour. While age counts, other factors are also responsible for Cerebral Palsy.

5.2.2 Children’s age and sex
Cerebral palsy affects children of all ages. The severity of the effects of cerebral palsy become more visible as the child grows. This is identified, by a child’s inability to attain milestones at the right stage. As a consequence this study encompassed children from the age of 6 months to about 12 years, solely with the view that six months was the stage at which milestones become clearly visible. While the sex of a child has no bearing on the effects of cerebral palsy, the condition affects both sexes.

5.2.3 Parents Responses to the rehabilitation of Child
Generally, reactions and copying strategies towards the disability of the child reflect the maturity of the parents, which is also highly related to the age of the parents. Many of the male respondents in this study can be termed as mature persons. This is because all the male parents were twenty-five years and above. Therefore on the premise of maturity, these male parents would be expected to cope better with the disability needs of their children. However this does not always prevail.

5.2.4 Effect of size of family on rehabilitation of Child
The higher the number of children in a family, the more favourable are effects of Social rehabilitation of the child. Family members often cushion the "burden"of caring for the disabled child by acting as social support system.
However, from an economic point of view, a larger family size poses a challenge on competing for resources for various needs. In this study, all the respondents had one or more children. According to the United Nations Children’s Fund (1985) “the greater the chance of a child’s survival, the less the parents’ need to bear more children than they actually want”. From the above statement, it may be inferred that in a situation where there is a disabled child in the family parents may tend to attempt to have more children to compensate for the disabled one.

5.2.5 Religious Beliefs of Parents

From a religious point of view, the moral and religious convictions of people have always provided people with a sense of purpose and a reason for expending their energies. Moral and religious convictions as well as the whole realm of values influence reality – inner reality and outer behaviour. Religious beliefs highly influence the behaviour of parents in coping with problems that relate to children with difficulties.

5.2.6 Educational Characteristics of Parents

Education lies at the very centre of efforts to help “poor people” in this case disabled children in their struggle to obtain the basic necessities of life such as food, shelter, rehabilitation and a secure future. Education has a positive effect on rehabilitation of the child. Parents with a sufficient level of education would be more predisposed to encouraging rehabilitation of the child.
5.2.7 Income of Respondents

Higher incomes among respondents save to foster rehabilitation. On the other hand, respondents with lower income sometimes experience withdrawal of their children from school and rehabilitation facilities. Other hurdles may include late enrolment of children, leading to low progression rate, increasing illiteracy among children of school going age and lack of rehabilitation.

The source of income for respondents also relates to rehabilitation. From the results, it is evident that parents' access to wage employment in the formal sector was extremely limited, especially for female parents. Although history reveals that women's proportionate share in wage employment increased in the post-independence period, women continued to be marginally integrated in the informal sector. However in the present study, the results were not consistent with the above view as the study findings revealed that most men were also in the informal sector, a particularly interesting revelation. This is especially so in consideration of previous studies which all indicate that women's proportionate share in employment in the informal sector is higher than that of men (Bardouille, 1991).

From the above scenario, we may deduce that the closure of industries in Ndola (the study site) left many male parents in the informal sector. Female parents on the other hand tended to be preoccupied with other services including caring for their children. It may also be stated that due to the low level of educated female parents indicated in the study, those parents may not have had access to income which would enable them to get involved in petty
trading; a common occupation for females that often contribute to income
generation.

Petty retailing of food items, mainly fresh vegetables and fruits, require little
working capital; can be performed without additional labour other than the
owner/proprietor herself/himself. It requires little or no education and skills and
can be performed both from home and market places. Moreover, parents,
more commonly, women can combine household chores and childcare
together with petty trading activities reducing the challenge of rehabilitation

Income for most of the parents in the present study could be referred to as
low, especially as evidenced by their low levels of education. Most female
respondents did not have stable sources of income, as they were not in formal
employment. The implication of women's concentration in a few economic
activities, such as trading, may be linked to their earnings and profit levels.
Although reporting on earnings and profits data is not always correct, it is
nevertheless instructive. The male parents in the informal sector were also
engaged in activities that were more lucrative compared to those of female
parents such as transport, manufacturing, auto-repair etc. which women do
not often engage in due to socio-cultural constraints. Therefore, gender is a
critical variable in female and male's access to certain types of economic
activities even in the informal sector.
While these disparities exist, another concern was the ability to provide the essential commodities needed for the home. According to Chisanga and Chigunta (1999), the Central Statistical Office observed that an average family needed K235, 000 per month to manage the basic requirements for a month around the period when the study was conducted 1996-1998 (Consumer Price Index 1998). In this present study, only twenty percent of the respondents could manage to buy these basic requirements per month. Most likely, parents of children with cerebral palsy in Ndola fell outside the boundary of the twenty percent who could manage the basic needs.

5.2.8 Gender Bias regarding children in rehabilitation

Although there were no notable differences regarding gender of a child and whether the parents would prefer to send either a boy or girl child for rehabilitation, observation indicated that the bias was usually against girl children. There seemed to be more boy than girl children that were reported to be attending social rehabilitation. There was no plausible explanation for the above gender picture. However, one view, that can be advanced for this picture may be traced back to our Zambian traditional culture. Traditionally, parents preferred to send their boy children to schools or rehabilitation than their girl children whom they believed could get married and be easily looked after by their husbands. Girl children therefore had limited opportunities to proceed with their education or rehabilitation compared to their boy counterparts.
5.3. Rehabilitation

5.3.1 Challenges of Rehabilitation

Various rehabilitation and disability organisations and other sources have identified some major factors that are closely associated with problems of rehabilitation in most developing countries. These are limited rehabilitation centres, low levels of education of parents with disabled children, limited access to essential services, lack of home or community based care or rehabilitation services. Others are poor attitude of parents towards their disabled children, lack of social welfare benefits to parents and families of the disabled, limited employment opportunities and slow success from rehabilitation (Rehabilitation International 1999, Times of Zambia, December 1998).

5.4 Challenges of Rehabilitation by Sex of parents

In households where there were both female and male parents (couples) aged below twenty-five years, both male and female typically experienced great challenges, while households without male parents had even greater difficulties.

Parents also tended to experience difficulties in basic needs and services such as transport money for taking the disabled children to rehabilitation centres, money to purchase wheelchairs, resources for hiring maids or help in caring for the disabled children. Other challenges of rehabilitation expressed by the female-headed households in particular included the lack of help in cooking for the family, children not enrolled or attending any educational or
rehabilitation institution. Such parents were also of low level of education and lacked health facilities.

This investigation first examined the observed differences in problems of rehabilitation between female and male parents in Ndola urban. The idea was to find out whether the differences in problems varied significantly by selected background characteristics (age, marital status, and education levels) and deprivation indicators (Lack of other people to help take care of the disabled child such as, maid, sisters, other siblings and access to rehabilitation services and facilities). This was aimed at determining significant factors that influence rehabilitation.

The U.N. argue that rehabilitation involves home intervention and institutional care, where a child attends or is enrolled in an institution for training often covering exercises, training in Activities for Daily Living known as ADL. This is considered absolute in nature because parents or households are expected to meet certain fixed standards necessary for the child to be rehabilitated, such as those referred to above regarding basic needs. On the other hand, it is observed that deprivation of basic services required to manage a child with a disability is part of what constitutes challenges. Social or human challenges which manifest themselves when individuals or parents lack essential amenities and capabilities.

Notably, literacy and nutritional information needed for the survival of a disabled child is an important aspect. This is because when parents lack
these skills, they are not only deprived of income but also human capabilities. This assertion is consolidated by the fact that within the broad category ‘parents’, some parents suffer more than others, particularly parents of children with cerebral palsy, female parents, and the very young parents as well as the aged. Therefore, as part of the rehabilitation process, income should be considered as one of the options people have rather than it being the ultimate in improving their general welfare (UNDP, 1997).

From earlier views, it can be deduced that in discussing the question of rehabilitation, according to the social approach, problems of rehabilitation exist when parents or guardians are deprived of income, resources, services and opportunities that are considered minimal in the given society. However, it is relative in nature because individuals or parents compare their rehabilitation needs or living standards in relation to others within the community or society or between nations.

It should be eminent here that rehabilitation difficulties are a feature of a majority of developing countries with disabled individuals or children. Many parents are not only deprived of basic rehabilitation needs for their children’s welfare but also experience huge disadvantages and gaps between parents with ‘normal’ children and those with disabled children. The use of the concept of rehabilitation challenges on the other hand is largely associated with developed countries. Like wise, with this approach rehabilitation hurdles exist when as indicated earlier, some basic capabilities for parents to cope are absent.
The basic capabilities include caring for the disabled, being well nourished, training in performing certain tasks necessary for daily living of a disabled child such as being able to bath themselves, or someone to help them do it, exercising through physiotherapy which gives stimulation to the affected child. Other capabilities include prevention from illness and having access to information or/and education. Recent years have shown increasing awareness in understanding of effects of parent's activities on all facets of their children's rehabilitation and welfare (Gascoigne, 1996). However, this is not the reality in many parts of the world and certainly not in Ndola, hence the investigation.

5.5 Gender Roles and Rehabilitation

The roles parents play become quite complex when in a family a child with a disability is born. Female parents especially, are faced with numerous responsibilities and challenges than male parents. This is especially so because of gender stereotyping, which tends to ascribe certain activities to a particular sex. Among the activities explored were problems of caring, cooking, feeding the children, cleaning the house, and schooling. These factors were taken into consideration because although they may appear basic, they present great demands upon the parents.

Gender is a difficult facet to explore, because as pointed out earlier, the roles that female and male parents perform or engage in are determined by society. Gender also involves analysis of socio-economic variables such as roles played, responsibilities, constraints, potential and opportunities of men and
women, which give rise to the relations between them (Oakley, 1985). These roles have specific cultural determination, specific to each particular society. The roles parents play in urban setups are not always explicitly outlined making the socialization process difficult as it is not bent on inculcating responsibilities in the young early enough. Female responsibilities and opportunities markedly differ from those of the men folk.

In certain traditional Zambian culture for example, women predominantly engage in agriculture and performing household chores which also include minute-to-minute care for children. Research also revealed that in traditional setups women mainly undertook economic activities, although the credit and benefit was accrued to men. Women were expected to give the men or husbands as many children as God would permit them. The responsibility of the welfare of the children also was vested in the mothers. The most intriguing type of service was that accruing to the man from the woman was the comfort, health and cleanliness of the man, whose responsibility was left solely to women (Ngulube, 1998). Although not all of the above gender roles outlined prevail in urban societies, few that are practiced pose a challenge to parents and especially to parents of disabled children.

5.6 The challenge of awareness of disability

Another challenge for such parents was that of awareness of their child's disability. Cerebral Palsy is a disability that is not easily identifiable as reported earlier. Therefore, parents had difficulties in becoming aware of their child's disability. Some parents reported to have identified their child's
disability at birth, a few days after birth while it took some time for other parents to become aware of their child's disability. In this study, fourteen percent of the parents became aware of their child's disability at birth. An anomaly either physical or behavioral was clearly observed at this stage, which indicated that the child could be a cerebral palsy case or simply disabled. Other parents indicated that they became aware of the child's disability within the course of the first year of the child's birth. Consequently, seventy percent of the children in this study were disabled both physically and mentally. However, Drew et al. (1988) observed that youngsters identified to be slow before age six are often severely or profoundly disabled.

Nevertheless, in this study, the degree of disability could not be determined as particular interest was placed on cases of children with diagnoses from centers, or hospitals and the observed features of affected children. Hence it was not easy to clearly determine the degree of disability of those children that were studied.

5.7 Parents' Response to rehabilitation

As disabled children grow older, the household chores coupled with other factors become amazingly complex. From historical patterns of behavior, an interesting feature of urban life evolved from the importance placed on earnings. As wage earnings became a regular and preferred source of livelihood, a growing proportion of men settled in towns permanently or for long periods and cut down on their visits to home villages. A growing number of men migrated with their wives to their employment centres but still many
more women were left without husbands. Women that had followed their men folk in towns became even more dependent on men as they were not allowed to work and they no longer depended on the land. They found their way to the towns but still faced conventions that made it impossible for them to get gainful employment that further made them become even more dependent on men (op.cit.1989).

From the early 1950s onwards the government ceased to impede the influx of women into urban systems but decades of urban hostility to female urbanization inflicted a lasting injury on the women's economic prospects. Their sex was held to disqualify them from heavy manual labour, although they were, and still are, the chief source of labour in traditional farming communities. As regards lighter work in domestic service, manufacturing and the distributive trades, men, by virtue of being first-comers to the urban centres, established a monopoly which women have not seriously challenged because they were conditioned to the convention that their proper function is to serve the family and manage household affairs (Turok, 1989). However, this has changed to some extent.

The marginalization of women in society is not only true in Zambia; it continues to be distressingly universal. In relations between women and men, most countries, experience tensions that obstruct women's full participation in the social, economical, and political life of the community. In many cultures, there are indications that power and the control of resources lie more with men than women. Prejudice against the empowerment of and autonomy of
women has been manifest through out history and is brought into sharper relief by the limited number of instances where women broke through the culture of male dominance that shackled their development. According to Kelly, (1996) women experience social patterns of discrimination through out their lives. So universal is this discrimination, and so pervasive and subtle are its manifestations. The insidious outcome has been that until very recently most men and some women themselves including virtually all children accepted this status quo. That it was self-evident that the proper and most unique role of a woman was as a wife, mother, provider for the family and a subordinate companion/helpmate to a husband. This included the fact that a woman was considered a domestic worker, a dependent person, who in many cases enjoyed little right to life of her own (op.cit 1996).

Gender roles play a pivotal role in social rehabilitation. For instance, the gender role of cooking was viewed as the duty of the female parents (wife). From the results of the study it was revealed that most women and all of the men in the study indicated that cooking for their families was the responsibility of the female parent. Others such as siblings, nieces, sisters or aunties were expected to help but the larger part of the work still remained that of the female parent. Only in very few cases was the male parent viewed as able to help in cooking. It was also observed that most of the families were living as a nuclear family. Evidently, most families could not afford to employ a maid, while the siblings in most cases were younger than the disabled children under consideration and so could not do much in terms of helping the parents
in household chores. This left most of the work especially cooking to be a sole responsibility of the female parent.

An attempt was made to find out actions of parents in rehabilitating children with cerebral palsy or whether parents had involved their children in any form of rehabilitation. Emphasis was placed on which parents - female or male were involved in the rehabilitation of their children. Concerns raised included whether the child was involved in rehabilitation, if involved in rehabilitation, what type of rehabilitation, place of preference for rehabilitation, parents' contribution to the child's' rehabilitation. Results indicated that most parents were involved in one form of rehabilitation of their children.

5.8 Parents' understanding of Rehabilitation

When asked about whether parents understood the meaning of rehabilitation, sixty percent of the respondents did not understand what rehabilitation meant. A few, representing forty percent showed a bit of understanding and used words such as repairing, correcting, improving, teaching, putting something in order and restoring. Their attempts were not too far from the true meaning of rehabilitation. However, they could not tell the intricate details that rehabilitation involved. Many were familiar with only one type of rehabilitation, namely physiotherapy. From a gender perspective, about thirty-seven women did not know what rehabilitation meant. Only twenty percent of the male parents did not know what rehabilitation meant. This gender disparity in the understanding of the meaning of Rehabilitation could be linked to the respondents' educational level. As shown earlier, most female parents' level
of education was low. The researcher could not find an equivalent word for rehabilitation in the local language mostly spoken in Ndola-the study site. Rehabilitation was therefore not translated in the local language and was asked as;

"Do you know the meaning of rehabilitation?" literally translated in the Bemba local language as;

"Bushe mwalishiba ifyo rehabilitation ipilibula?"

Asking the parents a question with an English word in between may have contributed to the high level of female parents; expressing ignorance of the meaning of the word. Once a parent expressed that they did not know what rehabilitation meant, the researcher, then explained the meaning of rehabilitation to the respondents by giving examples. This was done as a way of helping the respondents deal with the question that followed, which was whether their children needed rehabilitation?

When prodded on whether their children needed rehabilitation? Sixty percent of the parents agreed that their child needed rehabilitation particularly as regards performance of activities like sitting, standing, walking, talking, toileting, dressing and eating. This further clearly indicated that parents faced challenges of rehabilitation. Above all, physiotherapy was required by about twenty three percent of parents. On the other hand eleven percent indicated schooling was required for children to be able to read and write. Most parents were also aware of the availability of rehabilitation programmes in their own locality. About sixty percent of the female parents and sixty six percent of the
male parents respectively had knowledge of the existence of programmes and names of the institutions that were offering rehabilitation services. Those mentioned included the following Community Based Rehabilitation (CBR) centres. The Holy Family, Cheshire Home, Dagama Hospital in Luanshya, Chifubu Community Based Rehabilitation (CBR) Centre, Mushili CBR, Chipulukusu CBR, Kansenshi Basic School, Catholic- Kwacha Centre, Child Adoption Centre, Arthur Davison Hospital and Ndola Central Hospital centre.

As a result of the need for child progression, fifty four percent had their children enrolled or enlisted in programmes for transformation with a few enrolled in school, representing about eight percent, while only about eleven percent of the parents provided home care to their children. Expectations of child improvement were high as almost eighty nine percent of all the parents expected their children to achieve something in life. Interestingly, all the women expected their children to achieve something in life, as opposed to sixty nine percent of men who positively expected so. Parental expectations of their children does play a major role in rehabilitation.

Parents’ conceptions of the kind of work they expected their children to perform included doctor, nurse, teacher, driver, and social worker. Some parents desired that their children would be able to help those in similar situations later on in life by becoming nuns or missionary workers. Women were more optimistic about their children’s achievement than men who presented a rather pessimistic attitude to most issues on child achievement.
In a way women were more hopeful than men. Hope is a very positive emotion. It keeps people going when all is against them. Hope is what keeps parents trying and fighting for the best possible provision for their child. It keeps many parents looking for a ‘cure’ for their child’s difficulties some of which may be blind solace; but some of which may turn out to be appropriate help. It is therefore, essential that men should emulate women in hoping for better outcomes in their attempts of searching for the ‘cure’ to the problems of their disabled children.

In conclusion, this chapter has addressed pertinent issues surrounding rehabilitation.
CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSION

The study showed that both female and male parents faced challenges of rehabilitation concerning their children with cerebral Palsy. Significantly, female parents had greater challenges than male parents.

From the results obtained, one could conclude that some of the socio-economic characteristics of respondents had significant relationship with the challenges of rehabilitation of the children with cerebral Palsy. For example, there was significant relationship between female parents' level of education and their source of income. Most of the female parents were less educated than the male parents and significantly did not indicate any occupation compared to their male counterparts.

Female parents faced the greatest challenges in mobility to various places. Parents desired transport services. The reason for requiring transport was that children quite often required medical attention to be taken to hospitals, physiotherapy and school.

One of the biggest challenges of parents was that of providing adequate food to their children, a reason that was pointing to poverty in the households. This could also be attributed to the poor performance of the economy. Parents also
desired their children to have physiotherapy services and to be taught daily living activities as a way of promoting mobility and independence.

6.2 RECOMMENDATIONS

Individual level

- It is incumbent upon the individual parents to take initiatives to seek ways and means of rehabilitating their children. Specialists such as Doctors, nurses, physiotherapists and professionals in fields related to care of children with special needs, should embark on sensitization sessions to foster positive expectations in parents for their children.

- The lack of acceptance of the problem of disability stands in the way of treatment. Parents should try to come to terms with the problem of cerebral palsy early enough, if they are to start rehabilitating their children early enough. Denial well directed in the search for cures to the problem may well give positive result.

- Parents need help from counselors and social workers to understand that siblings in the home of the child with cerebral palsy also need attention. Counselors can help parents know that spending time for themselves as parents is important. Having a disabled child is a difficult aspect but it is not the end of the world. Self-pity and blaming others for inadequacies would render misery and even neglect of other children.

- It is also incumbent upon the parents especially the male parents to share certain tasks with their wives so that women are not disadvantaged and have their “burden” minimized.
• Individual parents should also endeavor to provide adequate nutritious food as part of the process of rehabilitating their children.

• Benefits from rehabilitation are not instant. Therefore, parents need to be patient enough for them to expect success in the rehabilitation programmes. Individual parents should never despair but keep on searching and applying strategies that could work for their children.

• Both female and male parents and the siblings to the disabled child must be involved in rehabilitating the disabled child. Although each child’s case may differ from other children, parents with disabled children must be meeting to share information and news on how they can rehabilitate their children. Parents can help each other and together contribute to the formulation of workable solutions to the children’s problem through open sharing.

Organisational level

• Organisations and institutions that rehabilitate the disabled and those that offer intervention programmes for severely affected children need to publicise their programmes so that all people concerned with children’s welfare get to know them and their services.

• More organisations should be put up for rehabilitation programmes. This is to ensure that the programmes are brought much closer to the people who need them. Moreover, some organisations could be offering different services but which would all be needed by the children and the parents. Institutions that can rehabilitate cerebral palsy cases should especially be promoted.
• Organisations and individuals should help in facilitating the production of material and equipment needed for rehabilitating the children. Such material may include pamphlets, books, crutches, standing frames, chairs and other essential material that specialists together with parents could be using in rehabilitating children. In Lusaka, some of these items are being produced by Paper Technology Zambia and Disacare. Companies in other towns can take up this challenge.

• Gender education in rehabilitation is also necessary. Organisations should spear head and facilitate the educating of people on gender attitudes, roles and their implications on rehabilitation. Emphasis should be placed on how gender education can effectively be tackled to ensure that no one group is disadvantaged as the case may be with women today.

**Governmental level**

• Government should encourage and formulate policies that would encourage the education and employment of women in various fields currently assumed to be the domain of men.

• Government should also spearhead and facilitate the establishment of schools and institutions for the rehabilitation of children who are severely disabled. Government should also strive to have trained specialists such as counsellors, teachers, and other professionals in the special field of disability to handle severe cases and should also make available relevant material for use by the specialists and the children affected.
• Government should consider giving free medical treatment and assessment for children and families who are in this situation.

• Mobile programmes should also be encouraged for purposes of identifying severely disabled children. In cases where the parents find it difficult to be taking their children for rehabilitation at established institutions, home visits by physiotherapists, nurses and doctors to give the required medical attention should be encouraged.

• Government should initiate workshops for parents with disabled children, where professionals such as nutritionists could teach parents how to prepare nutritious food for the children who cannot chew or swallow solid foods.

• Government should consider parents of disabled children as also being vulnerable, unlike the case where only the children are considered so.

• Government should also help parents purchase special equipment which parents cannot afford to buy. Items like blenders to liquidise food, wheel chairs, mats for training the children etc. could be provided.

• Government should introduce and encourage physiotherapy in the homes.

• Government must consider introducing Day Care Centres for severely disabled children to ease the “burden” on parents. At the centres, the parents could be taking turns in caring or looking after disabled children and also have time to do other activities like shopping, business and performing other duties when it is not their turn to look after the children.
REFERENCES


APPENDIX 1

PARENT AND GUARDIAN INTERVIEW INSTRUCTIONS:

I am interested in getting a general view of challenges faced by male and female parents of children with cerebral palsy. I will ask you to tell me about (x name of child). To help me understand the challenges and rehabilitation practices, I would like to get some idea of the concerns that you face in caring for your child and actions you take in bringing up your child. One set of Questions will comprise of background information about you as well as the child's. The other set of questions will be about challenges of rehabilitation and actions that you take-to try and rehabilitate your child.
SECTION A

BACKGROUND CHARACTERISTICS

Q1. Sex of parent
   1. Female [ ]  2. Male [ ]

Q2. Age (in years)
   1. Below 15 [ ]
   2. 15.1-25 [ ]
   3. 25.1-35 [ ]
   4. 35.1-45 [ ]
   5. Above 45 [ ]

Q3. Marital status
   1. Married [ ]
   2. Widowed [ ]
   3. Single [ ]
   4. Divorced [ ]
   5. Other specify ---------------------

Q4. Relationship to the child? -----------------

Q5. How many other children/ siblings and dependents do you have apart from x child?
   1. None [ ]
   2. 1-3 [ ]
   3. 4-6 [ ]
   4. 7-9 [ ]
   5. More than 10 [ ]

Q6. Religious denomination
   1. Catholic [ ]
   2. Protestant [ ]
   3. Muslim [ ]
   4. Watch Tower [ ]
   5. Other (specify) ---------------------
Q7. Education
1. Grade 7 and below [ ]
2. Grade 8-9 [ ]
3. Grade 10-12 [ ]
4. College certificate [ ]
5. University education [ ]

Q8 occupation
1. Formal Employment [ ]
2. Informal employment [ ]
3. Self-employed [ ]
4. None [ ]
5. Other (specify) ------------------------

Q9. Monthly Income
1. Below K100, 000.00
2. K101, 000.00 - K200, 000.00
3. K201, 000.00 - K400, 000.00
4. K401, 000.00 - K600, 000.00
5. K601, 000.00 - K800, 000.00
6. Above K1000, 000-00

CHILD'S BACKGROUND

Q10. Sex of child
1. Girl [ ]
2. Boy [ ]

Q11. Age of child
1. 7 months to 1 year [ ]
2. 1.1 - 5 years [ ]
3. 5.1 - 10 years [ ]
4. 10.1 - 15 years [ ]

Q12. What position is x child in the family?
1. First born [ ]
2. Second [ ]
3. Third [ ]
4. Fourth [ ]
5. Other Specify ------------------------

Q13. What is your child's condition known as?
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Q14. When did you become aware of x child's condition?
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Q15. When you become aware of X child's disability what were your immediate reactions?

1. Shattering experience [ ]
2. Did not know what to do [ ]
3. Other (specify) -----------------------------------------------

Q16. Did you have any conception of how you were going to cope?

1. Yes [ ]
2. No [ ]

Q16b. If yes to question 16, how did you expect to cope?

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SECTION B

CHALLENGES AND ACTIONS

Q17a. Do you face any problems with x child?

1. Yes [ ]
2. No [ ]

Q17b. If yes, what challenges do you face in caring for (X) Child?

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Q18. What would you say are the major problems you face with x child?

-----------------------------------------------------------------

Q19. What are your responses to these major problems?

-----------------------------------------------------------------

Q20. What are your worries, concerns or fears for x child?

-----------------------------------------------------------------

Q21. Do you expect x child to achieve something in life?

1. Yes [ ]
2. No [ ]

Q21b. If yes, what do you expect x child to achieve in life?

1. Be able to start walking [ ]
2. Be able to become independent [ ]
3. Start talking [ ]
4. Be able to work [ ]
5. Other (specify) [ ]

Q21c. If No, Why?

-----------------------------------------------------------------
Q22. Are there any specific areas of interest in which you expect x child to excel?
   1. Yes [ ]  2. No [ ]

Q22b. If yes, what are these specific concerns or interests?

Q23. What actions are you taking to ensure that your concerns come true?

GENDER QUESTIONS

Q24. If x child was a girl/boy do you think that your challenges would have been different?
   1. Yes [ ]  2. No [ ]

Q24b. If yes, to the above question, why do you say the challenges would have been different?

Q24c. If No, Why would the challenges not be different?

Q25. Do you think children such as x child should be treated differently from their boys/girls counterparts?
   1. Yes [ ]  2. No [ ]

Q25b. If yes, why?

Q25c. If No, why not?

Q26. What challenges do you face concerning the following?
   1. Feeding  
   2. Caring  
   3. Exercising the child  
   4. Sending x child to school or rehabilitation centre  
   5. Putting x child to sleep at night or during the day?
Q26b. What actions do you take or are you taking to deal with the above challenges?

1. Feeding
2. Exercising
3. Schooling/Rehabilitation
4. Sleeping Problems

Q27. Who do you expect to assist in the care of x child?

1. Mother
2. Father
3. Grand parents
4. Maid
5. Siblings

Q27b. Who assists you with the care of x child?


1. Cooking
2. Cleaning the house
3. Attending to other children
4. Performing all other tasks

Q29. Who actually does the above-mentioned tasks?

1. Cooking
2. Cleaning
3. Attending to other children
4. Perform all other tasks

Q30. Is x child required to perform any of these tasks?

1. Clean plates
2. Sweep the house
3. Cook
4. Wash Clothes
5. Other Specify

Q31. What kind of food does x child eat, or what do you feed her/him with?

1. Porridge, 2 Liquidised foods, 3 Anything, 4 Other (specify)
2. Porridge only
3. Liquidised foods
4. Any thing
5. Everything
6. Other? (Specify)
Q32. What do you understand by rehabilitation?

Q 33. Do you think x child needs rehabilitation?

Q33b If yes, what rehabilitation do you wish/expect x child to receive?
   1. Physiotherapy
   2. Schooling
   3. Speech therapy
   4. Daily Living activities
   5. Other Specify

Q34. Is X Child involved in any rehabilitation programme?

Q34b. If yes, What?
   1. Home care
   2. Institution care
   3. School
   4. Physiotherapy
   5. Community based rehabilitation

Q34c. If Not in any rehabilitation, what challenges prevent that?

Q35. Where would you prefer rehabilitation for x child to take place?
   1. At home
   2. In community based programme
   3. In Hospital
   4. At school
   5. Other (specify) 

Q36. Have you observed any benefits from rehabilitation of X child?

Q36b. If yes what benefits have you observed?

Q37. What is your contribution to x child's rehabilitation?

Q38. What tasks do you do with x child
   1. Gardening
   2. Watching Television
   3. Walking
   4. Other Specify
Q39. What do you say to encourage x child?

Q40. Are you aware of any rehabilitation programmes in your area (Ndola)?

Q41 If yes, what kind of programme are /they/ do you know?

Q42. What help would you require?

Thank you for your Cooperation